

Autism Listening Sessions: Summary of Comments

NOTE: This summary reflects the comments and suggestions made by individuals who attended the Autism Listening Sessions sponsored by CDC in four regions of the U.S. (August – November 2004) and from individuals who submitted comments through the CDC website. This summary is neither a CDC position statement nor a consensus document.

Background

Autism is a serious developmental disability with lifelong consequences for the affected child and his or her family. Several recent studies using established criteria for diagnosing autism spectrum disorders, such as Asperger's disorder and pervasive developmental disabilities, have reported prevalence rates ranging from 2 to 6 per 1,000 children. These rates are much higher than those reported a decade or more ago. Several explanations are being considered for this increase in autism, including administrative changes (such as evolving diagnostic criteria); better awareness of the disorder; changes in risk factors; childhood vaccines and their components (in particular the preservative thimerosal); increased exposure to antibiotics and food additives; and ambient environmental exposures (for example, pesticides and heavy metals).

No matter what the causes, the burden of autism is significant on the children and adults living with autism, their families, and the systems that serve them. The Centers for Disease Control and Prevention (CDC) considers autism an urgent health problem in need of targeted public health action.

In response, Dr. Julie Gerberding, Director of the CDC, directed staff to develop and implement a process to better understand the public's concern about autism and to obtain input into the research activities the public felt CDC should be conducting to address this urgent health problem. CDC participates in the Interagency Autism Coordinating Committee (IACC), a congressionally-mandated committee that serves to enhance coordination and effectiveness of autism research and service activities across the federal government and with public stakeholders. The IACC has recently developed a ten-year autism research agenda, which includes input from multiple federal agencies and stakeholders and includes CDC's current and future research plans. The framework of the IACC research agenda can be accessed online at: www.nimh.nih.gov/autismiacc.

The following broad areas represent the portion of the IACC agenda relating specifically to CDC's autism activities:

- ☐ Monitoring the prevalence of autism to determine trends over time and to identify those groups at higher risk.
- ☐ Conducting public health research on potential causes and risk factors, including investigations into potential environmental and chemical influences.
- ☐ Educating the public about the importance of early screening and intervention for children with autism.

Autism Listening Sessions

In 2004, CDC held a series of four open meetings to solicit the public's comments and input regarding CDC's priorities for autism interventions and research. CDC used the IACC autism research agenda as the framework for these discussions with the public. The four listening sessions were held from August through November 2004 at the following locations:

- ❑ The University of Miami's James W. McLamore Executive Education Center in Coral Gables, Florida. (27 August 2004) (60 participants)
- ❑ The University of California - Davis's M.I.N.D. Institute in Sacramento, California. (28 September 2004) (27 participants)
- ❑ The Indianapolis Convention Center in Indianapolis, Indiana. (22 October 2004) (102 participants)
- ❑ The Mount Sinai Medical Center in New York, New York. (14 November 2004) (21 participants)

A number of public and private entities, including the Dan Marino Foundation, the National Alliance for Autism Research, the MIND Institute, the Autism Society of America, and Cure Autism Now co-sponsored these meetings. Invitations were distributed widely to academicians, public health and health care professionals, families with children with autism, advocates, and other interested individuals. Each of the meetings consisted of brief presentations on CDC's portion of the IACC autism research agenda, a two to four-hour listening session facilitated by a trained professional, and a wrap-up session facilitated by CDC's Chief Science Officer, Dr. Dixie Snider. Participants who did not want to share their comments orally were encouraged to fill in comment cards that were available at all sessions; 34 written comments were submitted at the listening sessions. In addition, a web-site was developed to allow input via email for those unable to attend the sessions; 106 additional comments have been submitted by email to date.

Major Themes

The following is a summary of the major issues of concern raised and suggestions expressed by individual participants at the listening sessions. The purpose of each listening session was to gather individual input, rather than seek a consensus of opinion. This summary does not constitute consensus opinion of those participating in the listening sessions nor does it reflect a prioritization of the issues raised. As this is a summary, not every concern or suggestion made during the four public sessions is included explicitly, however this summary provides an accurate reflection of the major issues raised.

The input, suggestions, and questions received from the listening session participants fell into five major theme areas (in no particular order):

- Research
- Vaccine-related comments
- Public awareness and education
- Early detection, diagnosis and intervention
- Insurance and services provision

Research Comments

The research suggestions fell into three primary areas: etiologic research (genetics, co-existing conditions, environmental causes), surveillance and tracking, and treatment. Following are the major comments and suggestions from the listening session participants pertinent to each research area:

Comments Regarding Etiologic Research

Genetics—There was a general recognition that genetics plays an important role in the etiology of autism and that genetic research should be pursued. However, there was also concern expressed by some participants that genetic research too often is given priority over environmental research. Suggestions were made to extend the focus of genetic research to identify how genetic susceptibility might interact with environmental exposures. Specific suggestions included the hypothesis that a subset of children might be more susceptible to exposures (such as vaccines or environmental chemicals and heavy metals) as well as to interventions and treatments (such as from certain dietary or other treatments). It was also suggested that research into genetic factors or markers might be enhanced by comparing familial cases with isolated cases.

Co-morbidities—Some participants stated that there is a need to better understand the natural history of autism and the factors or diseases that co-occur with autism. This is important for targeting treatments that are specific to various expressions of the disorder. Similarly, such variations were also considered a rich area for research into causes of autism. It was also expressed by some that classifying the disorder based on the presence or absence of clinical features (for example, the level of cognitive ability or verbal ability or expression) could enhance the likelihood of understanding the causes of autism.

Environmental Causes—A number of potential risk factors deserve research attention, including exposures during pregnancy and early childhood. Various theories presented include:

- Environmental exposures, including chemicals (for example, pesticides and plasticizers), mold and mycotoxins, fluoride in drinking water, and heavy metals in fish.
- Maternal factors, including use of prescription medications, birth control pills, fertility drugs, and other assistive reproductive technologies.
- Maternal medical conditions, including autoimmune diseases, hypothyroidism, and viral infections during pregnancy.
- Pharmaceutical exposures in early childhood, including use of psychotropic drugs and antibiotics.

It was also suggested that these issues should be explored, not just in isolation, but as cumulative and combination exposures *in utero* and in early childhood.

Comments Regarding Surveillance and Tracking

The inconsistency in the definition of autism used by various service providers has led to challenges in accurately identifying children with this disorder.

In certain geographical areas, the diagnosis is not given because of insurance reimbursement-related issues. Some participants stated that because of this, current estimates of the prevalence of autism are underestimates.

There is a concentration of surveillance activities in the eastern United States and in California, leaving the remainder of the country under-represented in the effort to track and understand autism prevalence.

Tracking efforts and trend analyses need to be available by specific demographic subgroups, such as race or ethnicity (particularly for Hispanics), sex, and specific type of autism. Having such data would facilitate more accurate understanding of the burden in these subgroups and might identify groups in which changes in prevalence are more pronounced.

Alternative approaches are needed to address the complex issue of trends in autism. One suggested design was a multiple community sample that would carefully survey the entire population.

Comments Regarding Treatment

Finding a cure or effective treatment is an urgent research priority.

Develop a common methodology for treatment studies so that it would be easier to compare one study with another.

Develop interventions specific to the type of autism. There are many unconventional or alternative therapies and treatment approaches that have been suggested for autism, including nutritional supplements, dietary restrictions, and chelation therapy. Many parents and clinicians reported benefits from these treatments. An evidence base needs to be developed for the more promising of these alternative therapies.

Define what is judged to be “success” in a treatment protocol (for example, clinically meaningful improvement in functioning).

Sensitive measures of effect or outcome for treatment studies are needed.

Conduct a systematic assessment of the usefulness of current treatments, including their effects on the natural history of the disorder and their outcomes. A national case registry of this information (with ongoing analysis of the data) would provide helpful guidance for the development of clinical or best practice guidelines, while treatment trials progress.

Vaccine-Related Comments

The safety of vaccines, including concerns about the potential harms associated with cumulative exposure to the mercury-based preservative thimerosal, was a significant concern at some of the listening sessions. Below are the major comments and suggestions related to this subject:

Some parents, researchers and others do not trust CDC's position on vaccine safety issues, due in part to the perception of a conflict of interest between CDC's immunization recommendation and education program and its immunization safety activities.

Although CDC has conducted research and independent scientific reviews to address the specific concerns of parents and providers about the safety of vaccines, including thimerosal-containing vaccines, the perceived conflict of interest has resulted in a lack of confidence by some members of the public in CDC-sponsored research studies on this issue.

Engage a broader range of scientists and professionals in autism research.

Institute an oversight board for guidance on federal vaccine safety and autism research.

Separate CDC's immunization recommendations and education program from its vaccine safety program.

Allow easier access to CDC vaccine safety data for external investigator-initiated studies.

Research should be done on additional vaccine safety concerns, such as:

- The potential adverse health effects of other ingredients in vaccines, such as aluminum and formaldehyde.
- The health effects from cumulative exposures and combination exposures.
- The role of genetic susceptibility and vaccine adverse events.
- The interaction of vaccines with other exposures (for example, food additives and antibiotics).
- The long-term follow-up of children who experienced adverse vaccine reactions.

Remove mercury from all vaccines.

Reevaluate the safety of the current immunization schedule for children, particularly timing and spacing issues.

Public Awareness and Education Comments

Following are the major comments and suggestions received regarding this theme:

Some participants stated that CDC's efforts to increase awareness of autism were important. Public awareness and education needs to reach other critical audiences beyond parents and health care professionals, particularly child care instructors and teachers who interact with children on a daily basis. Teaching parents and others who interact with young children about the early warning signs of autism are critical to early identification.

Other participants stated that public awareness and education to dispel some of the fear and stigma associated with autism will help with earlier recognition and with the integration of families of children with autism into the mainstream of society.

Early Detection, Diagnosis, and Intervention Comments

Following are the major comments and suggestions received regarding this theme:

Some parents recalled long delays in their child's diagnosis and entry into early intervention despite their recognition that something was wrong.

Better communication and openness on the part of health care providers to listen to parents' concerns are essential in achieving timely diagnoses.

Pediatricians' training in the early recognition of autism is vital to achieving timely diagnoses. Training of health care professionals needs to begin early in medical school and in residency programs.

Addressing the fear of an autism diagnosis from a parent's and provider's perspective is necessary to encourage more open communication between them.

Best diagnostic procedures need to be identified and made the standard of practice.

Knowing the physical symptoms that are often reported by parents to accompany autism (for example, gastrointestinal problems) might be helpful to health care providers in identifying children who are more likely to warrant further diagnostic evaluation. Similarly, a better understanding of the early markers of autism (for example, large head circumference) might be a way to achieve earlier diagnosis and treatment for high-risk children.

Parents need guidance in managing their children once a diagnosis is made. A straightforward protocol (and resources) for managing a child with autism is needed for parents and other caregivers with newly diagnosed children.

Little is known about Asperger disorder or about autism in adults. Because Asperger disorder is more challenging to diagnose and because it is more recently recognized than autistic disorder, there is little knowledge about its natural history and the effectiveness of interventions.

There is a dearth of information on and services for adults with autism. There is great need to address the major issues in autism treatment and services across the lifespan.

Insurance and Services Provision Comments

Following are the major comments and suggestions received regarding this theme:

Some participants emphasized that early identification is important but that its benefits are only realized if high-quality services are available. Development and implementation of a best practice model would help alleviate discrimination in the quality and types of services children receive.

Specific services and reimbursement issues raised by some participants included:

- Lack of specialized services in many areas (particularly for speech and occupational services).
- Fragmented services across the lifespan (for example, difficulty in transitioning a child with autism from pediatric into adult care).
- Delays in receiving services.
- Limited insurance coverage for services (for example, income thresholds for service eligibility, little or no coverage for alternative therapies).
- Unique challenges for certain subgroups in getting appropriate evaluations and services (for example, for minorities and those on Medicaid and Medicare).
- Variation in accessibility and quality of services across jurisdictions.
- Insurance coverage for children falling along the autism spectrum, specifically, those with diagnoses of pervasive developmental disorder and Asperger disorder.

Some participants stated that there are few, if any, services specific to adolescents and adults with autism. This lack of services poses significant challenges for families and social systems as high numbers of affected children transition into adulthood.

General Issues

Participants also raised some general issues that cut across all or many of the themes summarized above.

- A need for parents to be an integral partner in the search for the causes, prevention, and treatment of autism. They have critical insights into their child's functioning that can be helpful in achieving an earlier diagnosis, developing more effective interventions, and identifying fruitful areas for etiologic research.
- A desire to collaborate more closely with CDC to address autism research and intervention issues and priorities.
- A sense of urgency that more be done immediately in the area of intervention and treatment for children who have autism.
- A perception of government agencies being unresponsive to parents' concerns about the causes, treatment and prevention of autism; of health care providers being unwilling to listen attentively and respond to parents' concerns about their child's development and use of "alternative" therapies that many parents believe offer benefits; and of service providers being inattentive because specialized services are not adequately available and flexible.

- A sense of urgency about the need to acknowledge the high rate of autism reported in the United States and in other countries; this urgency should be embodied in the language used to describe the high rate and indicated a preference for such terms as “national crisis,” “epidemic,” and “emergency.” This sense of urgency was coupled with frustration that not enough was being done to understand autism causes, prevention and treatment.
- An appreciation expressed towards CDC for holding these sessions as this demonstrated a commitment by CDC to listen to the concerns of the various communities across the U.S.

CDC appreciates the chance to hear directly from parents and others concerned about autism. CDC is considering a number of steps that can be taken to address the concerns raised and suggestions made by listening session participants. CDC will make these action steps available publicly on its website, www.cdc.gov, when finalized.